

Annual report from the Nordic Network on CHARGE to the Nordic Leader Forum of Deafblindness, 2026

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Members:

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Aim and purpose for the network:

The target of the Network is to collect, share, and spread knowledge of CHARGE syndrome.

- **Collect knowledge:** We keep each other updated within the network with, for example, reports from the national CHARGE networks and DBI CHARGE.
- **Share experiences:** We emphasize sharing all aspects of knowledge and experience within the CHARGE syndrome. This is important because we have a relatively small population in the Nordic countries and CHARGE itself is rare.
- **Spread knowledge:** We work on disseminating what we learn and the voices of people living with CHARGE.

Meetings:

Since April 2025 we have met online 8 times with the whole network. That is more than usual but several meetings were shorter just to keep the timeline for producing the webinar on the Case studies from re-CHARGE. During a few longer meetings we have also shared news from our activities in our respective countries.

In May we met for two days in Enköping, Sweden. During these days we participated in a DBI CHARGE webinar with Timothy Hartsthorne, worked with the structure for our two upcoming webinars and had a meeting with NVC discussing: “how to do it”, regarding both technic, layout and content of the webinars. We visited a daily activities centre and one residential home of Mo Gård where, among others, individuals with CHARGE work and live.

Activities:

This year has focused on writing manuscripts for and recording the webinar on the case studies. This was aired in January with a live Q&A session.

During a CHARGE theme day in Stockholm Sweden organized by the Swedish workgroup on CHARGE syndrome and the Center for rare diagnosis our Swedish members did a presentation of the publication as well.

Plans and activities for the future:

We will:

- **Continue to work with webinars on the publication re-CHARGE** – in the autumn of 2026 the second one, on the chapters with interviews, will be held.
- **Include people with CHARGE more:** We want to amplify the voices of people living with

CHARGE.

- **Create a welcome pack for parents:** This will include a letter, toy, information for parents (book), and the interview chapter with the mother from re-CHARGE.
- **Create a welcome pack for doctors and nurses:** This will be for BVC and healthcare professionals.
- Participate in NVC deafblind conference in Denmark in September 2026 with information on the network, the re-CHARGE publication and upcoming webinar available.